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Citation for published version:

Kydonaki, K, Kean, S & Tocher, J 2020, 'Family INvolvement in inTensive care: A qualitative exploration of critically ill patients, their families and critical care nurses (INpuT study)', *Journal of Clinical Nursing*, vol. 29, no. 7-8, pp. 1115-1128. <https://doi.org/10.1111/jocn.15175>

Digital Object Identifier (DOI):

[10.1111/jocn.15175](https://doi.org/10.1111/jocn.15175)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Peer reviewed version

Published In:

Journal of Clinical Nursing

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Family INvolvement in inTensive care: a qualitative exploration of critically ill patients, their families and critical care nurses (INpuT study).

Journal:	<i>Journal of Clinical Nursing</i>
Manuscript ID	JCN-2019-1011.R2
Manuscript Type:	Original Article
Keywords:	Critical Care, Family Care, Family-Centred Care, Focus Groups, Grounded Theory, Intensive Care, Interviews, Nursing, Nursing Care, Patient-Centred Care

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TITLE: Family INvolvement in inTensive care: a qualitative exploration of critically ill patients, their families and critical care nurses (INpuT study).

For Peer Review

ABSTRACT

Aims and objectives: To understand the different factors that impact on the involvement of adult family members in the care of critically ill patients from the perspective of patients, families and nurses, with the aim to inform the enactment of a patient and family-centred care (PFCC) intervention to support the patient-family-nurse partnership in care involvement.

Background: Existing evidence **lacks** theoretical underpinning and clarity to support enactment of patient and family-centred care and involvement of families in the care of the critically ill patient.

Design: Qualitative exploratory design using thematic analysis.

Methods: This study was conducted at two adult intensive care units (ICU) in two tertiary University Hospitals in the central belt of Scotland. Between 2013 and 2014, we conducted semi-structured interviews with critically ill survivors (n=19) and adult family members (n=21), and five focus groups with nurses (n=15) across both settings. Data were digitally recorded, transcribed verbatim, and uploaded in NVivo10. Data were analysed thematically using a constructivist epistemology. Ethical approval was obtained prior to data collection. Data are reported according to the Consolidated Criteria for reporting qualitative research (COREQ) checklist.

Results: Family's situational awareness; the perceived self in care partnership; rapport and trust; and personal and family attributes were the main factors that affected family involvement in care. Two key themes were identified as principles to enact PFCC in adult ICUs; "Need for 'Doing family'" and "Negotiations in care involvement".

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Conclusions: Negotiating involvement in care requires consideration of patients’ and family members’ values of doing family and the development of a constructive patient-family-nurses’ partnership.

Relevance to clinical practice: Future policy and research should consider patients’ and family’s needs to demonstrate family bonds within a negotiated process in care participation, when developing tools and frameworks to promote PFCC in adult intensive care units.

Keywords: Family, Intensive Care Units, Patient participation, Grounded theory, Focus groups, interview, critical care nursing.

What does this paper contribute to the wider global clinical community?

- Factors that impact on the operationalisation of Patient and Family-Centred Care (PFCC) in ICU relate to FMs’ situational awareness; the perceived self in care partnership; rapport and trust; and personal and family attributes.
- Family members selected activities that provided emotional and psychological support to their critically ill family members.
- The ‘Need for Doing family’ and ‘Negotiations in care involvement’ describe dimensions of family involvement in care that need to be considered when enacting a PFCC approach to critical care.

INTRODUCTION

An increasing emphasis on improving the service user experience with the focus explicitly on the promotion of Patient and Family-Centred Care (PFCC) across the health and social care sector is well supported by international (IHI, 2014, WHO, 2007) and national (CQC, 2008) organisations. PFCC is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients and families (Johnson and Abraham, 2012). This approach shifts the balance of power between healthcare professionals and the person needing care, as seen in the paternalistic healthcare system of the past, to a more collaborative approach.

Patients do not exist in a vacuum and most are embedded in family systems. This has implications for intensive care (ICU) patients at a time of limited decision-making capacity, and PFCC is a means to look after the patient as well as the family. Any involvement of a family member (FM) should be grounded in a negotiated and mutually beneficial partnership between patients, families and health care professionals (Kean, 2010).

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BACKGROUND

Several conceptual frameworks for PFCC have been used in community and paediatric nursing (Johnson and Abraham, 2012), as well as critical care (White et al., 2018, Davidson, 2010), but there is little insight and guidance into its commissioning in adult critical care by policy makers and clinicians (AHRQ, 2013). The fact that we are living in times of constant change, contextual factors of care delivery make the translation of the core concepts of PFCC challenging in every day practice. Whilst PFCC has recognised international importance, most evidence of successful implementation of PFCC in adult critical care comes from out with the UK (Rose et al., 2019). An integrative review by Mitchell et al (2016) on PFCC interventions in adult ICUs identified that the majority of interventions focused on information provision and communication as part of interaction between clinicians and FM/patients, with few studies reporting the participation of FM in ward rounds (Mitchell et al., 2016). Olding et al’s (2016) scoping review of 124 studies examining patient and family participation in ICU described five elements of involvement as an expression of PFCC: (i) presence, (ii) having needs met/being supported, (iii) communication, (iv) decision-making, and (v) contributing to care (Olding et al., 2016). Both reviews stressed that PFCC interventions were widely diverse, and lacked theoretical underpinning and clarity to support enactment of PFCC throughout the ICU stay.

We approached this study based on the PFCC philosophy and initially envisaged to identify care activities acceptable to patients, FM and nurses in order to develop a bundle of care as an approach to enact PFCC in ICU settings. This more pragmatic focus on designing a care bundle was driven by the funder and the expectations for a clinical outcome of this study. However, over the course of the

study our thinking progressed from description of care activities to theorising thus
informing the theoretical basis for enacting PFCC in adult ICU care.

For Peer Review

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METHODS

Aims

We aimed to explore patients', adult FM and nurses' perspectives of family involvement in care in ICU and (1) to identify the factors that impact on their involvement and (2) to develop a theoretical understanding of these factors in order to operationalise PFCC in adult ICU. The findings reported from this study correspond to Stage 1 of the Medical Research Council framework (Craig et al., 2008).

Design

Our epistemological stance was informed by constructivism, accepting that there is more than one reality and that reality is informed by our experiences (Howell, 2013). We used an Applied Thematic Analysis approach (Guest et al., 2012). Data were collected and analysed simultaneously, using open and focused coding strategies and theoretical sampling. Data analyses ceased once we had reached saturation of the emerging themes exploring stakeholders' perceptions of family involvement in the care of their critically ill patients.

Settings and participants

The study was conducted in two general ICUs in two tertiary teaching hospitals in Central Scotland. ICU1 and ICU2 had 16 and 18 beds respectively and a patient-nurse ratio of 1:1. Both ICUs have an open visiting policy; however, ICU2 encouraged visitation within a more restricted time frame (2-7pm). We used a purposive sample of patients/ FM and nurses. We included ICU patients with an ICU length of stay more than 2 days, to increase the opportunities of having had a FM

visited, and who had mental capacity at the time of interviewing after their discharge from ICU but before their discharge to the community. We included patient participants regardless whether they had been admitted as an emergency or as an elective patient since we did not aim to make any correlational analysis of confounders and level of involvement of FM during the patient's ICU stay. FM were defined as adult individuals who visit the patient in ICU and have a close, continuing relationship with the patient. [We did not exclude patient/ FM participants from different cultural or religious backgrounds.](#) In both ICUs, critical care nurses had a range of nursing experience, thus allowing us to explore their perceptions of family involvement in care across novice and expert nurses.

Data Collection

Between 2013 and 2014, we conducted semi-structured individual interviews with ICU survivors and adult FM and Focus Groups (FGs) with ICU nurses. We sought to pair ICU patient and FM wherever possible in order to explore their perceptions of care involvement within one family unit. The rationale for this strategy is based on prior research insights (Kean, 2010) that drew attention to the importance of relationships within families when thinking about care involvement. Based on our epistemological stance, we assumed that ICU patients and their FM might hold different views on involvement in care; interviewing them individually allowed for a higher level of privacy for both groups to express their views and concerns freely, if they wished to do so. When FM requested being interviewed with another FM, we allowed for relationship-based dyadic interviews, which focus on the co-construction of meaning (Morgan, 2016), similar to FGs. We used FGs to explore ICU nurses' perceptions and experiences of family involvement in care (Kitzinger

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and Barbour, 1999) as well as their views on suitable care activities for family integration into care.

We developed an interview topic guide based on the literature and the reflecting insights from the developing data analysis. This strategy allowed for the eventual data sufficiency of themes. All participants were asked about their understanding of ‘family involvement in care’ and factors affecting this. This question served as a baseline, reflecting the different perceptions and realities of participants. ICU nurses were also asked about any challenges they may face in delivering PFCC.

Interviews and FGs lasted between 60 and 90 minutes, were digitally recorded, transcribed verbatim for data analysis and checked for transcription accuracy before data were uploaded into NVivo 10 for data analysis. All three authors (KK, SK, JT) conducted interviews, paired up for FGs and prepared reflective field notes, which were shared in regular meetings.

Ethical considerations

Ethical approval was secured by the local Research Ethics Committee prior to the study. Participants volunteered to participate in the interviews and FGs and consented prior to the recording. Patient and FM participants were initially approached by the research nurse who provided an information sheet. The researchers were informed about participant availability and consented the patient/FM. Anonymity and confidentiality was maintained throughout the study.

Data analysis

Data were analyzed using an inductive - abductive approach in developing themes. Our analytical approach reflects strategies from applied thematic analysis (Guest et al., 2012). Data analysis was an iterative process and started, as soon as the first interviews were transcribed. Two researchers (KK, SK) independently read and re-read each transcript and started initial open coding, involving the deconstruction of text and data reduction method. We developed focused codes resulting in a codebook. The coding scheme and codebook development was discussed, revised and adjusted on an ongoing basis by all three researchers (KK, SK, JT) in order to maintain consistency in data analysis and allow comparisons made, creation of categories on higher abstraction levels which, in turn, is essential for developing themes on a latent level (DeCuir-Gunby et al., 2011). By going forward and backwards between data and focused codes/ theme development we ensured that the resulting two major themes reflect the links between different focused codes across the data set. This process included abduction as strategy since theme development on a latent level is theoretically informed (Guest et al., 2012). Thematic saturation was reached when we observed a rapid decrease in new codes and an increase in the frequency of assigned codes, categories and themes (Guest et al., 2012) after 30 interviews were analysed.

Rigour

Credibility was achieved by allowing time at the beginning of the interview and FGs to build trust and rapport. Our process of developing, discussing and revising codes, categories and themes, and the use of a codebook offered consistency in data analysis and increased the credibility of our analysis. Transcripts were checked

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for accuracy before uploading into NVivo 10. Transferability of our findings was enhanced by the inclusion of diverse stakeholders and the advanced data analysis to theory development. All three researchers maintained a reflexive account during data collection and analysis to ensure confirmability. The data are reported based on the Consolidated Criteria for reporting qualitative research (COREQ) checklist (See Supplementary File 1).

For Peer Review

RESULTS

Demographics

ICU survivors and Family members

Nineteen ICU patients were recruited (7 from ICU1 and 12 from ICU2) and 21 adult FM (11 from ICU1 and 10 from ICU2). Eleven interviews were paired (6 from ICU1 and 5 from ICU2) whilst 13 interviews were not (3 from ICU1 and 10 from ICU2). Whilst pairing was our main strategy, this was not always possible due to the FM declining the invitation (n=1), the patient not having mental capacity at the time of interview (n=1), and the FM not visiting before the patient was discharged to the community (n=12). In five of the 11 paired interviews, more than one adult FM participated. Fifteen of the ICU survivors were male, and only four were female (Table 1). In contrast, 16 FM were female, and five were male (Table 2). All patient and FM participants were of white origin predominantly British with the exception of two patients who were from Northern European countries.

[Insert Table 1. ICU survivors' demographics (N = 19)]

[Insert Table 2. Family members' demographics (N = 21)]

ICU Nurses

Across both ICUs, 15 ICU nurses participated in five FGs. Initially we planned to conduct three FGs at each site. The unpredictability of staff workload led to the repeated cancelation of one scheduled FG in one ICU.

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Nurses’ demographics are presented in Table 3. Apart from two participants, nurses with less than two years ICU experience had rotated in from other areas such as High Dependency or Theatres and in one case from a different ICU.

[Insert Table 3. Nurse participants’ demographics (3FG in ICU1, 2FG in ICU2)]

We identified two major themes that describe principles of enactment of PFCC: (a) Need for ‘Doing family’ and (b) Negotiations in care involvement. We explored factors for enacting PFCC, which included: FM perceived situational awareness of the complexity of care; the perceived self in a care partnership; the development of rapport and trust between nurses and FM in a care partnership; and the personal and family values and attributes that affected involvement of FM in care. Supporting quotes are presented in text and in Table 4.

[Insert Table 4. Supporting data. Factors affecting involvement in care.]

Perceived factors for enacting PFCC

a. FMs’ perceived situational awareness of the complexity of care

Eleven of the FM (61%, n=21) perceived their involvement in the care of the patient minimal and limited to ‘being there’ by sitting at the bedside. FM and patients felt often overwhelmed and apprehensive with the ICU environment as it felt “unknown, intimidating and scary” to them, often referring to the equipment used (presence of ventilators and monitors), the complexity of care and/ or the risk of infection for the patient (quotes, table 4). Most FM pointed to the complexity of care in ICU suggesting that they “did not have the expertise and [it] was not safe for the

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3 *patient*" (FM12, FM5, FM7, FM8, FM13) for them to get involved actively in physical
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5 care activities, hence narrowed their involvement in holding the patient's hand.
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8 9 10 **b. Perceiving self in care partnership**

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12 Participants discussed their role within the patient-FM-nurse triad relationship
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14 and how this role may influence the instigation of FM involvement in care. From ICU
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16 nurses' perspective, they felt accountable for the care of patients and their families
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18 and some were hesitant involving FM in care for two main reasons: a. to avoid the
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20 risk of slips and errors and b. to protect the FM from the burden of caring (quotes,
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22 Table 4). Nurses explained they spent time observing family dynamics and levels of
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24 intimacy, previous experience with the care of the patient (i.e. patients with long-term
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26 conditions), as well as the type of relationship with the patient before inviting a FM to
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28 participate in the patient's care (quotes, Table 4). Specifically, for participation in
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30 physical care activities, all nurses agreed that they felt more comfortable inviting FM
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32 after the acute phase, but that it would be the FM who would determine the level of
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34 involvement (quotes, Table 4).
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40 In both ICUs, visiting policies were open and flexible. Despite most nurses
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42 supporting an open visiting policy, some felt exposed and frustrated at times when
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44 some FM were constantly present at the bed space. Many nurses viewed
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46 themselves as advocates of their patients with the objective of providing care without
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48 interruptions. This was evident when they referred to their need of controlling to
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50 some extent when a FM can be present and involved in care (quotes, Table 4).
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54 Interestingly, some FM argued that they handed over the power of care to the
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56 clinicians once the patient was admitted to ICU. This step reassured the FM that
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their critically ill family member received the care and attention needed, as illustrated by FM 15 below:

“We literally handed over our dad to you, and you guys do your job...” (FM15)

At the same time, the role of the family was to preserve the patient’s dignity, provide emotional and psychological support by ‘being there’ and being/getting involved in decision-making. The quotes in Table 4 suggested that the presence and visits of the family offered a neutralising process to maintain the patient’s individuality and identity and to allow a means to coping with the threat of losing the patient. For instance, patient 14 recalled his family being there *“holding my hand when I was agitated and was trying to pull out my mask”* at a time when sedation agents were reduced.

FM also functioned as a link between the patient and clinicians by providing information about the patient prior to critical illness, their quality of life, habits, health and wellbeing, which helped clinicians to obtain a view of the patient as a person (quotes, Table 4). The wife of patient 6 highlighted how her input helped clinicians to distinguish disorganised thinking in her husband, who had delirium and inaccurately believed that his brother passed away from an accident.

“So, that’s very important in picking up delirium, what it is and what isn’t. And particularly, this latter story about the accident [of the patient’s brother] that reoccurred three weeks ago...that would not have been picked up by any medical staff...” (FM7)

Families had a very clear understanding and distinguished between nursing care and family care. The husband of a young female patient (P3) pointed out that his involvement in care aimed at *“doing something nice for her”* and he would like to be involved in her care as it made him *“feel I can help”* (FM4). The activities he chose were often to comfort, for example using a favourite body lotion or giving a foot massage, and thus aimed at maintaining the emotional bond between partners.

In relation to involvement in physical activities of care, there was agreement between patients, FM and nurses that *“nurses have control of the care in ICU”* (P8) and *“there is a fine line as to what can be expected from families to do”* (FM12); hence, it is nurses who should invite FM to participate in physical activities of care. Only two FM prompted their active involvement in physical activities without being invited by the bedside nurse, arguing that *“both the family and the patient should initiate such involvement in care”* (FM13, FM15). This is an important insight indicating that the ICU is often perceived as the nurses' territory and thus they should invite family participation in physical activities of care. Yet, some FM were proactively seeking more information to increase their situational awareness in order to support the patient:

“I’m nosy I suppose. I would quite like to know what all the different machines were doing. And I did ask so, I was given explanations for things. I think it’s just my own curiosity”. (FM12)

Patients, in contrast, often perceived themselves as receivers of this care partnership. Their role was passive reflecting that they, at times, lacked mental capacity and felt vulnerable. For patients, involvement in care was mainly about FM

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visiting and providing psychological support by being there. Patients were reassured by knowing that *“they were beside (me)”* (P10) (see also quotes in Table 4). Some patients were pragmatic about a possible family involvement in care. For instance, a young patient (P5) who had suffered a brain haemorrhage, said that it *“didn’t matter to me if my parents were involved in everything, even personal care, as I was really unwell”*. A similar view was expressed by an elderly patient about his wife’s participation in his care: *“I don’t draw a line, if care is needed, it’s needed”* (P6).

c. Trust and rapport in a care partnership

All participants perceived time to be an essential factor in the development of a caring relationship between nurses and FM, as rapport and trust is established through honest and frequent communications between nurses and FM. The need for frequent communications was valued by both nurses and FM. Nurses were mindful in adjusting their communication to lay language to facilitate the process of communication and increase FM’s and patient’s understanding of the critical situation (quotes, Table 4).

d. Personal & family attributes and how they affected involvement in care

There were personal and family attributes, such as age, gender, type of relationship, sense of dignity and level of intimacy that could explain the different perceptions of the level of FM contributions, in physical or emotional care activities. Most FM were female, expressing positive views regarding their participation in physical care activities, including intimate care compared to male FM. They considered such involvement a means of emotional affection to the patient. For instance, mothers were almost expecting to be involved in looking after their adult

child in ICU, similar to wives whose male partner was critically ill. Although FM did not feel the need to be involved in intimate care, their involvement clearly depended on their relationship and thus level of intimacy with the patient. In contrast, male FM whose female partner was ill, or in-laws and siblings were less comfortable with intimate care as illustrated in quotes in Table 4. Elderly male patients more frequently expressed that they did not want their family members to see them in a vulnerable position.

"I think as long as I knew they were beside me, that was enough for me you know" (P10).

"I would like her to be involved in warming my hand [...] this touchy feeling, it really matters, as it takes away the fear of isolation" (P2).

Participants were specifically asked about acceptable physical activities FM could be involved in. For all participants, technical and personal care were clearly viewed as nurses' job, and therefore most FM were reluctant to be involved in this type of care. Table 5 shows the distinctive types of technical activities that FM, patients and nurses found acceptable for FM to be actively involved in.

[Insert Table 5. Typology of physical care activities considered comfortable and less comfortable for FM to be involved in. Essentially, non-technical care that increased the comfort for a patient was acceptable to both FM and patients whilst technical and personal care was defined as professional care and thus is the realm of nurses.]

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Principles for enactment of PFCC

The analysis identified two main themes that describe the principles for enacting PFCC in ICU: (a) “Need for ‘Doing family’” and (b) “Negotiations in care involvement”.

Need for ‘Doing Family’

‘Doing family’ related to FM efforts to maintain the integrity and normality of the family unit while the patient was in ICU. By being there, FM aimed at grounding their ill family member in the everyday reality, supporting each other through a stressful time and sharing their experiences by ‘being there’. There was variation in how they achieved this, which related to the type of relationship and level of intimacy with the patient as well as their perceived roles in caring within families.

For example, the following expert is from a husband trying to maintain his wife’s daily bedtime routine whilst in ICU and on a ventilator.

Interviewer: When you’re talking about (name of patient) bedtime routine, is that what she normally does when she’s home?

FM4: “So, she would have a shower or whatever else and just get herself ready to bed. So, I’d help her put pyjamas on [...] she likes her bed socks on to keep her feet warm, so I would make sure she had them on. She likes her feet tucked in properly - she jokes about wolves getting her feet in the night - so the wolves can’t get her feet. The nurses don’t always know about that stuff. It’s just these little funny things to make her feel more comfortable with her surroundings.

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3 Similarly, nurses facilitated and worked together with the husband of a patient
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5 (P3) to maintain normality for this family by reflecting and considering the patient's (a
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7 mother) need to have a contact with her child, thus helping her to preserve her role
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9 as a mother, whilst also considering the need of the child to see her mother.
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15 *"The little one (name of daughter), she wouldn't come to me when I was tubed. That*
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17 *was totally breaking my heart and this nurse knew that. And so, she thought, if I'm*
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19 *sitting in a chair and if I'm in a café, (name of daughter) might find it easier to come*
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21 *and sit on my knee or to come near me. So, she (the nurse) was really sensitive to*
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23 *my family situation". (P3)*
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29 'Doing family' for this family meant to be supported by nurses in
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31 communicating and maintaining their family unit as much as it is possible in an ICU.
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33 'Being there' was also important for FMs when the prognosis was poor.
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38 *"Especially when you know that the prognosis is not good anyway but knowing how*
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40 *close you came is very difficult to deal with. So, trying to - not be falsely cheerful but*
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42 *try to give him something positive to look forward to". (FM2)*
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47 *"...I think just the involvement of being there, being allowed to touch him, to speak to*
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49 *him". (FM7)*
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Negotiations in care involvement

Negotiations, in our data, included discussions about the timely information provision and about being involved in the decision-making process.

Timely information provision

FM were sensitive to the fact that normality in life is interrupted when there is an episode of critical illness. The resulting uncertainty in patients’ outcomes and wellbeing created a demand and expectation in families for timely information, which would alleviate the anxiety about patients’ condition, prognosis, and recovery. Nurses updated the FM daily either when visiting or over the phone and organised formal consultations every two to three days. Confidential communication with the FM happened in private rooms in both ICUs. At times, FM took a more active role in participating in these consultations, although participation in ward rounds was not common practice in either ICU.

“One thing that I was invited to participate in and was really good, was the doctors’ rounds. The doctors were doing the round and I said to the nurse ‘do you mind if I stand in the back and I’ll keep quiet, I want to listen to what they are saying’. And the nurse said ‘oh, I don’t know about that, we’ll have to see what the doctor says’. And the doctor said ‘actually we encourage you to take part and to speak up and to give us your opinion’. And that was really good”. (FM10)

Negotiating time for consultation allowed FM to plan ahead and manage the demands of family life (e.g. childcare) and the patient’s need to ‘be there’. FM perceived the communication with clinicians effective when they were offered the

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3 opportunity to negotiate the time for consultation, considering the distance they had
4 to travel to the hospital, the routine of the ward, and the availability of staff. Yet,
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6 when these needs were not met, it increased the level of frustration and decisional
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8 uncertainty for the FM. For instance, the husband of P3 was not informed when his
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10 wife needed to be intubated overnight, which left him feeling undervalued and
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15 disempowered.
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19 *“Every time I left at night I said to the nurses: ‘if anything changes to the negative,*
20 *you need to give me a ring’ and there’s really only one night I should have had a call*
21 *at three or four o’clock in the morning (.) I was incredibly frustrated with that nurse.*
22 *It’s distinctly anger making not to be kept up to date and briefed as to what’s going*
23 *on”.* (FM4)
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33 On other occasions, FM were required to spend a lot of time in the waiting
34 room to be informed about the patient’s condition and progress, which also caused
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42 *FM17: “The worry that we’re going through with mum, and the waiting. We don’t want*
43 *to miss anything, so if we’re asking to see somebody, you sit in the room, because in*
44 *our head if we go downstairs have a tea, they come out the room, and you’re not*
45 *there...”*
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51 *FM16: “And then you don’t see them”.*
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Participation in decision-making

Being part of decision-making was an expectation expressed by all FM, which would help them understand and come to terms with what was happening with their ill family member.

“I suppose just being included in what’s being decided for the patient, and feeling that you have a part in it, that you’re part of a team, which is going to care for my husband...and feel less apprehensive because I know what’s going on.” (FM1)

FM demonstrated different levels of involvement in decision-making. Some were proactive and challenged decisions without being prompted by the nurses, whereas others were more passive and felt excluded. There was no association observed between the gender of the FM and their proactive attitude, but there was some connection with the educational background of the FM. For instance, the wife of P6, a scientist by background, accessed and read scientific literature and drew on expertise in their friendship circles, which allowed for a different understanding of her husband’s situation. She thought through alternatives and challenged her husband’s given diagnosis.

“Yep... that has been the principal I’d been working on from the beginning and hence, my more optimistic view and trying to keep up the moral. But other people were taking the other diagnosis [...] so I challenged the alternative diagnosis with the consultant”. (FM7)

Despite the fact that nurses felt that they met the FM information needs by informing them after the decision was made, FM expressed the wish to be more actively involved in the decision-making process.

“...to a certain extent or being told what decisions are being made and being able to say ‘well, I don’t like that’ or ‘I don’t think I could cope with that’, things like that”.

(FM1)

From the nurses’ perspective, it became clear that the responsibility of decisions stays with the clinicians, which contrasts with FM willingness to be involved from an early stage in the ICU stay and not only when the patient’s clinical condition appears to be stabilised.

(FG1, ICU1)

FN3: *“I’ve never had somebody demanding the treatment to be withdrawn, but I’ve had members demanding their treatment not be short”.*

MN2: *“The generalised view is when they’re [the patient] in the ICU side, as opposed to the HDU, most things are actually taken care by the nurse or the doctor, including decision-making because that’s potentially the most critical part. And the families don’t want to get involved in that [...] it’s later on down the line. I think they could get involved”.*

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DISCUSSION

This study set out developing a care bundle that could be implemented and tested in a future PFCC intervention study. We, initially, aimed to explore patients', FM and nurses' perceptions of involvement in physical care activities in ICU. However, over the course of the study and with our developing analysis, we realised that in order to develop an intervention that would work, we needed to understand, first, the factors that are affecting patient-FM-nurse partnership. This realisation resulted in the identification of key principles for the enactment of PFCC in ICU; Need for 'Doing family' and 'Negotiations in care involvement'. The inductive – abductive analysis led to a conceptual model for the enactment of PFCC in ICU considering the two key concepts as vehicles to its realisation (Figure 1).

[Insert figure 1]

It has become evident in our study that FM involvement in care ranges from relatively passive to active and from tangible contributions to physical care activities, such as bathing, massaging and cleaning to more intangible contributions such as moral and emotional support (Eggenberger and Nelms, 2007, Mitchell et al., 2009, Mitchell and Chaboyer, 2010, Olding et al., 2016). FM in this study were clear about the importance of their contribution to the emotional and psychological support of their ill family member rather than to their physical care. In contrast, intimate and personal care was clearly regarded as nursing care, only, by many family members and this needed to be considered for any future interventions.

Our data acknowledged the tension created by the complex and highly technical level of care provision in the ICU environment and the acuteness of the

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3 clinical situation, which may discourage FM from contributing actively to care. This is
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5 in comparison to other environments and clinical situations, including end-of-life care
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7 or paediatric settings, where FM contribution has been shown to be increasingly
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9 receptive by patients and families (Quinn et al., 2012, Rose et al., 2019). Less recent
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11 studies (Almerud et al., 2007, Fridh et al., 2007) have offered useful insights into how
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13 the technologically intensive landscape of ICU with complex medical equipment can
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15 be difficult for FM to understand and have recognised nurses' efforts to increase
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17 familiarity with the environment to improve situational awareness. Such awareness
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19 may facilitate FM to be involved more actively in decision-making.
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24 The relationship between FM and the nurses has received considerable
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26 attention in the literature (Paradis et al., 2013); yet the wider cultural factors that
27
28 impact on this relationship are largely under-researched. The perceived self in this
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30 care partnership was a key theme in our data, which has not been identified in the
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32 literature previously. Whilst nurses' role as active care givers and patients' role as
33
34 passive receivers of care was clear, FM varied in their perceived roles from passive
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36 to active. Existing literature on family involvement tends to view FM as vulnerable
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38 subjects and recipients of care or as resources for improving patient outcomes, but
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40 very rarely as individuals that can partner with the health care provider in the care of
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42 the patient (McAdam, 2008). Despite the open visiting policies in ICUs (Garrouste-
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44 Orgeas et al., 2010), our data highlighted that a cultural shift from families as
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46 recipients of care to active participants in care requires clinicians and FM to invest in
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48 time, to build trust and rapport and to recognise families' and patients' values and
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50 attributes.
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56 The concept 'Doing family' refers to two elements, which may overlap: the
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58 'family practices' in everyday, ordinary life, and the 'practices of intimacy' (Jamieson,
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2011). Morgan (2011) describes family practices as a set of activities in the family's life that create a sense of regularity, i.e. events that happen daily, weekly, monthly, annually or life events and have some effect on another FM (e.g. parenthood, partnering, sickness or bereavement) (Morgan, 2011). These practices are fluid and changeable as family boundaries change and are re-defined during the family's history; hence, family remains a complex and dynamic concept. FM need to get involved in care relates to their values in 'doing family' and thus their very specific sort of knowing, loving and being close to another person, which suggests 'a strong social desire to preserve principles of commitment and reciprocity that bind members of society together' (pg.1) (Chambers, 2012).

Intimacy was a distinctive concept derived from our data. For Jamieson (2011), intimacy is about our everyday relationships and affective interactions, and so practices of 'intimacy', as an aspect of family life, are those that enable, generate and sustain a subjective sense of closeness and being attuned and special to each other (Jamieson, 2011). Clinicians need to understand these subtle but important differences that account for the motivation and level of FM involvement in care in their efforts to operationalise PFCC.

Participating in decision-making was a significant element of negotiations in family involvement. In the last decade, the Health Foundation UK (2013) has focused on establishing Shared Decision-Making (SDM) in critical care provision. SDM is defined as a process in which patients/families are encouraged to participate in selecting appropriate treatments or management options (HF, 2013). This process is altered during critical illness, as the patient has limited mental capacity in being involved, and the doctor-patient relationship is replaced by intercommunication between family and healthcare professionals with significant challenges. First, it

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2
3 should be recognized that not all patients are willing to discuss their wishes with their
4 family, and this relates to the dynamics of the family, and the fluidity of 'doing family'.
5
6 Second, the family's perception of what the patient wants could be different to what
7 the patient actually wants, and this cannot be tested whilst the patient has limited
8 mental capacity. Third, there is a recognised risk that the family may make a
9 decision about the patient without clear situational awareness, creating a burden for
10 both the FM and the healthcare provider.
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19 For SDM to happen, certain principles need to be reflected, which were
20 suggested in the data and have been recognised in the literature. A sound
21 partnership between FM and healthcare staff is required. Clinicians need to invest
22 time to provide adequate information and support to FM, invest in building a
23 personalised relationship with the FM that is context sensitive, pay direct attention to
24 the needs of each specific situation considering the beliefs and values of the patient
25 and the family and negotiate care involvement (Elwyn et al., 2012, Paradis et al.,
26 2013). Negotiation is considered a communication strategy (Strauss, 1978, Smith
27 and Coleman, 2009) and, hence, careful attention should be paid on tailoring the
28 information provided, and engaging all parties in meaningful conversations in order
29 to enable a PFCC approach.
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44 Interpretation of our data led to the identification of four shared values that inform
45 our conceptual model for the enactment of PFCC in ICU. First, a mutual respect of
46 each stakeholder's perceived role in care, which is required to facilitate trustful
47 interactions. Second, nurses should respect the patient and family information needs
48 and show empathy in their communications and negotiations by providing timely
49 information and empowering participation and shared decision-making. Third,
50 involvement should be aimed to maintain normality in the patient's and family's
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temporary period of life, in order to preserve and ensure hope, dignity and safety in the care delivery. Forth, the participation in care cannot be mandated but supported by the clinicians, and so both patients and FM need to be consulted and consented about their level of involvement in care.

Limitations

This qualitative study has certain methodological limitations. This is a family-related study, and thus no claims can be made in relation to families-as-units. It was conducted in two Scottish ICUs, so findings cannot be generalised to other critical care areas in the UK or internationally. We acknowledge the low number of nurses that participated in the FG, and the impact on generalisability. We did not collect information about nurses’ qualifications, because there is no specific PFCC training in the UK nursing curriculum that would have had an impact on their approaches to family involvement in care. However, we managed to have a diversity in our sample, and saturation of data was achieved as no new themes emerged by the last FG. We did not collect information about patient characteristics, such as severity of illness, previous comorbidities, hospital length of stay, socio-economic, cultural or religious background of the patient or the FM to make a correlation analysis of the findings, as this was a qualitative in depth exploration of the participants’ perceptions. We recognise this as a limitation of the study and acknowledge that future intervention studies should consider such factors in correlational analysis.

CONCLUSION

To our knowledge, this was the first qualitative study to critically examine factors of affecting involvement in care from the patients', families' and nurses' perspective, and contribute to the theoretical development of enactment of PFCC in the critical care settings. Assessing family strengths as opposed to their weaknesses alone is essential to empower FM to adjust to the critical care situation, and increase their confidence and self-efficacy by enabling them to take control of their lives again. This can be achieved by facilitating 'doing family' and by 'negotiating' short-term care goals for FM involvement in the patient-FM-nurse partnership.

RELEVANCE TO CLINICAL PRACTICE

Future policies and behavioural change research should integrate shared values and principles that allow flexible individualised approaches to establish patient-FM-nurse partnerships and consider the concepts of 'doing family' and 'negotiating involvement in care' in their design and implementation. When tools and framework are developed to promote PFCC in adult intensive care units, consideration should be given to the patients' and FM need to preserve family bonds and allow for flexibility and negotiation in the process of family involvement in care.

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TABLES

Table 1. ICU survivors' demographics (N = 19)

Patient	Age	Gender	Reason for admission	ICU- LOS	Paired/non- paired
ICU1					
Patient 1 (P1)	63	M	Neurological – spine tumour	15	Paired
Patient 2 (P2)	29	M	Neurological - seizures	20	Paired
Patient 3 (P3)	30	F	Infection- Sepsis	16	Paired
Patient 4 (P4)	19	M	Infection	5	Paired
Patient 5 (P5)	23	M	Brain Haemorrhage	10	Paired
Patient 6 (P6)	74	M	Myasthenia Gravis	15	Paired
Patient 7 (P7)	57	F	Postoperative care	5	Non-paired
ICU2					
Patient 8 (P8)	62	M	Postoperative care	4	Paired
Patient 9 (P9)	78	F	Thoraco-abdominal aneurysm	6	Paired
Patient 10 (P10)	73	M	Sepsis	19	Paired
Patient 11 (P11)	63	M	Encephalopathy	10	Paired
Patient 12 (P12)	47	M	Liver transplant	4	Paired
Patient 13 (P13)	54	M	Postoperative care	3	Non-paired
Patient 14 (P14)	55	M	Postoperative care	20	Non-Paired
Patient 15 (P15)	36	M	Postoperative care	3	Non-paired
Patient 16 (P16)	45	M	Liver transplantation	4	Non-paired

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Patient 17 (P17)	65	M	Suicide attempt	7	Non-paired
Patient 18 (P18)	47	M	Oesophago- gastrectomy	8	Non-paired
Patient 19 (P19)	73	F	Pneumonia	7	Non-paired

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Table 2. Family members' demographics (N = 21)

Family member	Gender	Relationship with patient	Paired/ non-paired
ICU 1			
Family Member 1 (FM1)	F	Wife of P1	Paired
Family Member 2 (FM2)	F	Sister of P1	Paired
Family Member 3 (FM3)	F	Wife of P2	Paired
Family Member 4 (FM4)	M	Husband of P3	Paired
Family Member 5 (FM5)	F	Mother of P5	Paired
Family Member 6 (FM6)	M	Father of P5	Paired
Family Member 7 (FM7)	F	Wife of P6	Paired
Family Member 8 (FM8)	F	Mother of P4	Paired
Family Member 9 (FM9)	M	Father of P4	Paired
Family Member 10 (FM10)	M	Husband of P1	Non-paired
Family Member 11 (FM11)	F	Daughter of P1	Non-paired
ICU 2			
Family Member 12 (FM12)	F	Wife of P8	Paired
Family Member 13 (FM13)	F	Daughter-in-law of P9	Paired
Family Member 14 (FM14)	F	Wife of P10	Paired
Family Member 15 (FM15)	F	Daughter of P10	Paired
Family Member 16 (FM16)	F	Wife of P11	Paired
Family Member 17 (FM17)	M	Son of P11	Paired
Family Member 18 (FM18)	F	Wife of P12	Paired
Family Member 19 (FM19)	F	Wife of P2	Non-paired

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Family Member 20 (FM20)	F	Wife of P3	Non-paired
Family Member 21 (FM21)	F	Daughter of P4	Non-paired

For Peer Review

Table 3. Nurse participants' demographics (3FG in ICU1, 2FG in ICU2)

ICU 1 (N = 10)		ICU 2 (N =5)	
Gender	ICU Experience (in years)	Gender	ICU Experience (in years)
Male nurse (MN1)	12	Male nurse (MN5)	10
Male nurse (MN2)	25	Male nurse (MN6)	7
Male nurse (MN3)	12	Female nurse (FN7)	5 months
Male nurse (MN4)	8 months	Female nurse (FN8)	4
Female nurse (FN1)	13	Female nurse (FN9)	11
Female nurse (FN2)	4 months		
Female nurse (FN3)	10		
Female nurse (FN4)	6 months		
Female nurse (FN5)	1		
Female nurse (FN6)	15		

Table 4. Supporting data. Factors affecting involvement in care.

Factors affecting involvement in care	Supporting data
FM's situational awareness	
FM feeling overwhelmed and apprehensive	<p><i>"... she's at her death door and any little thing could have pushed her over the edge. This is what we felt... If we were to bring something in and somehow it contained germs that could have caused her an infection". (FM11)</i></p> <p><i>"It wasn't safe for me to do anything ... possibly touch hand or arm but nothing more than that". (FM7)</i></p>
Perceiving self in care partnership	
Nurses accountable for the patient and family	(FG5, ICU2)
a. to avoid the risk of slips and errors	<ul style="list-style-type: none">- Interviewer: <i>"What do you think you could involve FM in, if they expressed an interest"?</i>- FN8: <i>"Yeah, you always kind of think, is it allowed to let people come, you know, relatives wash their...you know...because it's kind of comes under our care".</i>- MN6: <i>"...I think things like mouth care like what happened today [FM helped in brushing patient's teeth], basic eye care, again, it depends on how many tubes, wires and all the rest of it are not".</i>- FN9: <i>"Yeah, I know, because if there are tubes, I wouldn't suggest to do mouth care".</i>

(FG4, ICU2)

- b. to protect
the FM
from the
burden of
caring
- MN5: *"Great if you knew everything is going to be pristine underneath; but you don't know what's oozed and what's leaked, if the patient's bowels have moved".*
 - FN7: *"I think it would be upsetting for family".*

(FG3, ICU1)

- MN4: *"...they're overwhelmed when they come in and they kind of take a step back there..."*
- FN6: *"Yes, I think sometimes, they're exhausted because their relative has been really ill and they've been really worried and actually when they're in here they know that they can stop worrying and they know that we'll do all the care".*

Assess family's (FG4, ICU2)

- capacity to be
involved in care
- FN7: *"...I find that it totally depends on the patient and their level of ICU stay. And some FM are really keen to get involved, they know what's going on and want to help, and then others aren't. So, I think it's gauging who kind of wants that and who doesn't".*
 - MN5: *"I think it's harder to gauge initially, gauge what the family are going to do or not do. Like some of them wait to get here whereas other families just want to sit there at the bedside the whole-time and..."*

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- FN7: *“Hold their hand sometimes, eh, just hold their hand”.*

(FG1, ICU1)

- FN2: *“as far as them being involved actually in physical care I think you just may hear that some families don’t want to participate, in as basic as mouth care or suctioning, they will shy away from it”*
- MN2: *“...if they’re used to helping at home, if it’s a patient with, er, kind of long term-condition, who’s with us for an acute period of time, but they’re used to having their relative’s involvement in their personal care at home”*
- FN3: *“I think it depends on the person because if you’ve got somebody who comes in and appears to understand the information you’re giving them, then, you sometimes try and involve them a bit earlier, but if you’ve got somebody who dumps and looks like they’re about to burst into tears, the alarm goes off and, you know, get really upset every time they’ve got a weak pulse or the patient coughs and they panic, then they’re not really ready to, you know”.*

Welcoming

(FG3, ICU1)

involvement in
care

- MN4: *“If it’s formal as an invite, I think you should always, make them feel like if they wanted to participate*

in certain areas that they could. But, I don't think you need to formally invite them to participate; I think you just need to foster that kind of feeling of well, listen, if you want to get involved here you can without saying..."

- FN6: *"Also, I think it's not them initiating it, but it's them determining what level of involvement".*

(FG1, ICU1)

- Interviewer: *"And at which stage do you think FM should be involved in care activities?"*
- MN1: *"Down, down the line [...] You have to take it on an individual basis, but it's generally in the processes well down the line, when they're on their way to getting better, definitely".*

Having control *(FG2, ICU1)*

and flexibility with
family presence

- FN1: *"I definitely like having my own choices...because it can depend how I feel on the day whether I'm really pleased to have [relatives] and make an effort to sort of befriend a relative and include them in the care or whether I just want to send them out for...when I'm doing the personal care. I like having that control..."*
- MN3: *"I think I'm probably with [nurse's name], in that I'm quite pragmatic about dealing with families, I don't think there's a rule that you could apply to any of them, and some people are more participative and need more*

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	<p><i>input from you. Some people you can see are more stand-offish and probably want sort of, er, validation and time away from everything in place. So, saying to people, you know, you need to go home, get sleep, get meals, and saying that it's okay to be away from there it's actually useful to them".</i></p> <p>- FN1: <i>"I think it's hugely individual and to do with the personalities, and my personality, their personality. I think it is usually the ones that almost maintain a vigil that I find I need that break from them, because they're just watching your every move".</i></p>
Shift of power from family to clinicians	<p><i>"And we go to a place where we didn't have clue what was happening. So we were sat down with the consultant etcetera and said 'listen, this is all the things that you and your colleagues - you put to us, and we need to understand what's the motivation for each one so we can (...) put a plan – we want to put a plan in place. So when is the tracheostomy gonna happen? At what point is that realistic?' So, ehm, and they were more than happy to do that". (FM4)</i></p>
FM as advocates of the patient	<p><i>"But when he very first woke up as well (.) he didn't actually want anyone to come and visit him. Not even his mum and dad. So, I said like 'shall I ring your dad? Do you want me to ring your mum?' that sort of thing, and he said 'can you text them to say I'm ok but say maybe come and visit after the weekend' [...] And so (.) it was a bit difficult for me because I</i></p>

knew obviously his family would want to come and see him (.) but I did feel like I was his spokesperson kind of thing (.) like he told me he didn't want them to come and so (.) I had to it was his wishes kind of thing". (FM3)

Patients as receivers of care *"...but I can fully appreciate that-uh, had I been (.) in a situation or in a condition that I couldn't do things like that, then yes it would have been great to have somebody sitting there the whole time to be able to say well I need, as you say, cream on or whatever. And, and again I'm - I'm sure it would help the (.) the person to-to feel like they were contributing as well so, yeah I think I - I think that would be really good". (P8)*

Trust and rapport

"I had to invest in a relationship with all the nurses and the consultants first...that allowed me to be part of the discussion" (FM4).

(FG1, ICU1)

- MN2: *"I notice the language... that a lot of nurses use when they shouldn't. There are easier ways of saying things [...], jargon is one that they should lose because it doesn't make you look smart, it just...separates you from communicating"*
- FN2: *"But, a lot of families don't...I don't know...jargon puts them off, the equipment puts them off if they're not familiar with anything medical".*

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Personal and family attributes	
	<p><i>“Ehm (.) when I was really poorly, I was really picky about who I would want, who I wanted to visit me. And I had a select group of people who were allowed to visit me. And the people who visited were my immediate family and several very good girl friends” (P3).</i></p> <p><i>“He (the patient) didn’t want them (patients’ parents) to see him in this weak phase. He is a dignified person” (FM3).</i></p> <p><i>“I (mother) would have liked to have been able to wash him (son). I would have liked to have been able to wash his hair, to clean him...to shave him” (FM8)</i></p> <p><i>“More than happy to be more involved, face wipe, trimming nails, but I would really try not to get in the way...definitely do bed-bathing” (FM3).</i></p> <p><i>“Bed-bathing is something that most relatives would rather nurses do it. I would be fine to do it, if asked, but I would prefer not to” (FM1).</i></p> <p><i>“I don’t actually think that she [wife] would have been comfortable with that [bed bathing] either, to be honest. You know, although we are very close that’s something that maybe</i></p>

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5 *She was a nurse and is very independent, so you don't want*
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7 *to take that away. So, my role was basic moral boosting"*
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Table 5. Typology of care activities considered comfortable and less comfortable for FM to be involved in. Essentially, non-technical care that increased the comfort for a patient was acceptable to both FMs and patients whilst technical and personal care was defined as professional care and thus is the realm of nurses.

Comfortable doing	Less comfortable doing
Combing hair	Bed bathing (intimate care)
Oral care	Technical care
Massaging with cream	
Bed bathing upper body	
Washing hair	
Assist with mobilization when extubated	

Manuscript: Family INvolvement in inTensive care: a qualitative exploration of critically ill patients, their families and critical care nurses (INpuT study).

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	9 and title page authors contribution table
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Title page
3. Occupation	What was their occupation at the time of the study?	Title page
4. Gender	Was the researcher male or female?	Title page
5. Experience and training	What experience or training did the researcher have?	Title page
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	10
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research.	7-10
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	7-10

Domain 2: study design		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	7-10
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	7
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	7
12. Sample size	How many participants were in the study?	11, tables 1, 2, 3
13. Non-participation	How many people refused to participate or dropped out? Reasons?	NA
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	7-9
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	7-9
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	11, tables 1, 2, 3
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	8-9
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	NA
19. Audio/visual	Did the research use audio or visual	8-9

recording	recording to collect the data?	
20. Field notes	Were field notes made during and/or after the inter view or focus group?	8-9
21. Duration	What was the duration of the interviews or focus group?	9
22. Data saturation	Was data saturation discussed?	8-9
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	8-10
Domain 3: analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	9-10
25. Description of the coding tree	Did authors provide a description of the coding tree?	9-10
26. Derivation of themes	Were themes identified in advance or derived from the data?	9-10
27. Software	What software, if applicable, was used to manage the data?	9-10
28. Participant checking	Did participants provide feedback on the findings?	9-10
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	13-23, table 4
30. Data and findings consistent	Was there consistency between the data presented and the findings?	13-23, table 4
31. Clarity of major themes	Were major themes clearly presented in the findings?	13-23
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	13-23

Figure 1. Conceptual model to enact PFCC in ICU

